



NASA Life Sciences Data Repositories:

Update on Data Access and Lessons Learned 2012

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NASA Data Repository Goals

Improve dissemination of and access to
NASA life sciences data and information

Goal of Today's Presentation

Set realistic expectations for access to
NASA data sets

NASA Repositories

Clinical Data Repository

Lifetime Surveillance of Astronaut Health (LSAH)

- Astronaut Clinical Data
- NASA's Occupational Surveillance Program
- Data collected to examine the incidence of acute & chronic morbidity and mortality of astronauts
- All astronauts selected into the US space program will be monitored throughout their NASA career and retirement from the astronaut corps

Research Data Repository

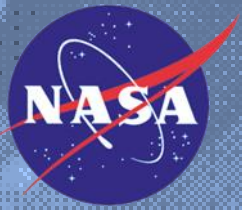
Life Sciences Data Archive (LSDA)

- Human Research Data (astronauts, ground subjects)
- Animal research data and biospecimens
- Data collected during NASA-funded life sciences research (Mercury to International Space Station(ISS), and ground studies)

Team Approach to Filling Data Requests

Evidence Based Working Group (EBWG) is the initial clearinghouse for request reviews

- Membership from both LSAH and LSDA repositories
- LSDA and LSAH will partner with each requester to understand their needs & provide the most relevant data...
...whether medical , research, or a combination of both
- Requests for attributable data referred to LSAH Policy Board
- 142 Data Requests Processed FY2011



Challenges

#1 De-Identification of Data

Challenge	Data Request Example(s)	Progress
<p>NASA human subject data are governed by the Privacy Act of 1974</p> <p>Several key factors render these data hard to de-identify (non-attributable to the subject)</p> <ul style="list-style-type: none"> •Small subject “n” •Gender •Public figures •Spaceflight experience •Duration is sometimes specific to mission 	<p>Intracranial pressure eyeball data (small number of subject)</p> <p>Brain Magnetic Resonance Images(MRIs)</p> <p>Space Motion Sickness(SMS)/SMS</p> <p>Medication across Shuttle flights</p>	<p>De-identified, pooled data are made available to requesters</p> <p>Where possible, research data (and limitations, constraints) will be made available on the LSDA website</p> <p>Continued development of de-identification procedures and other solutions</p> <ul style="list-style-type: none"> • (e.g. software solution to de-identify MRI metadata, other identifiers)

#2 Crewmember Consent

Challenge	Data Request Example(s)	Progress
<p>Crews must be “re-consented” for:</p> <ul style="list-style-type: none"> •Use of their medical data for research purposes •Use of their research data for reasons other than the original investigator’s informed consent <p>Consenting for each study is a time consuming process</p>	<p>Video of On-Orbit Crew Exercise</p> <p>Bone Densitometry (DXA) Data during Mir</p>	<p>Actions pertaining to data privacy were issued by JSC CPHS last year</p> <p>Final review and approval for LSAH and LSDA repositories expected in March 2012</p> <p>Re-consent process will begin shortly thereafter</p> <ul style="list-style-type: none"> •Prior to each ISS mission •Annual physical exams

#3 Requester Expectations

Challenge	Data Request Example(s)	Progress
<p>Setting user expectations regarding time to fill requests</p> <p>Many factors determine the simplicity or complexity of filling data requests:</p> <ul style="list-style-type: none"> •# of subjects •# parameters •Is informed consent needed? •Is attributable data required? •Completeness of data sets in repository •Data storage format in NASA systems •Manual retrieval of data •Level of statistical analysis required •Output format desired ...and many more! 	<p>Requester asking NASA for data only 2 days prior to proposal submission</p> <p>Dental Events in the Astronaut Corps-Hard Copy Records</p> <p>Note: While pdf files are electronic, the content is not fully searchable.</p>	<p>Work to improve communication with each requester to verify data needed and provide realistic schedule for each request</p> <p>Work to quantify data requests into general “small/medium/large” categories in terms of effort required will be provided with data request schedule early in the process</p>

#4 Gaps in the Research Repository

Challenge	Data Request Example(s)	Progress
<p>Caused by lack of data return to NASA</p> <p>Original meta data necessary to understand data set – need for collaboration with original investigator</p>	<p>In general, timely return of data to NASA improves our ability to then further utilize that data for data requests</p> <p>Experimental conditions about the data need to be well documented</p> <ul style="list-style-type: none"> •Time points of data collection •Medication usage •Exercise logs •etc. 	<p>Data return expectations set in new NASA Research Announcements (NRAs) and award letters</p> <p>Data submission agreement (DSA) established between investigator and LSDA</p> <p>Enabling communications between investigators</p> <p>Use of clinical data if applicable</p>

#5 Gaps in the Clinical Repository

Challenge	Data Request Example(s)	Progress
<p>“Documentation by Exception”</p> <ul style="list-style-type: none"> •Focus on clinical care and treating symptoms •Main focus was resolving complaint, not always determining etiology •Limited diagnoses •Data not collected with research design (i.e., ‘standardized data’) in mind •Data located in multiple places and in varying formats <p>Lead time for this type of data is long; data often must be manually abstracted/entered and data from multiple sources verified against one another</p>	<p>Medications are prescribed and available, but medication use may be poorly documented</p> <ul style="list-style-type: none"> •Incomplete or no information regarding dose, mode of administration, dates meds were started/stopped, effectiveness, side effects, adverse events •Sometimes only the drug class is provided (e.g., “sleep med taken”) •Contents of ISS medication kits only provides what medications and quantity are launched and returned, not individual use •Medication data, if it exists, may reside in several different locations....EMR, private medical conference, research protocol, post-mission medical debriefs – poor recollection regarding med use weeks or months ago 	<p>Significant efforts in last year to fill data gaps</p> <ul style="list-style-type: none"> •Manual abstraction of paper records, mission audio (Private Medical Conferences) •Verifying data integrity across multiple sources (e.g., NBL training records) <p>Work with physicians to document why a medical test was waived</p>

#6 Competing Customers

Challenge	Data Request Example(s)	Progress
<p>LSAH is NASA's occupational health program charged "to investigate and describe the incidence of acute and chronic morbidity and mortality of astronauts and to determine whether the unique occupational exposures encountered by astronauts are associated with increased risks of morbidity or mortality</p> <p>Supporting research data requests is currently outside the funding scope of LSAH</p>	<p>2009 Crew Health NRA</p> <ul style="list-style-type: none"> • Shuttle MRI data to validate models for Sonographic Astronaut Vertebral Examination (SAVE)--NNX10AM34G <p>2010 Crew Health NRA</p> <ul style="list-style-type: none"> • Request for brain MRI data for new investigation NNX11AR02G • Request for ISS crew interaction data for new investigation NNX12AB40G <p>Directed Research</p> <ul style="list-style-type: none"> • PI for recently concluded ISSMP Spinal Elongation experiment is interested in complementary data 	<p>When resources permit, LSAH still supports these research data requests</p> <p>LSAH is working with HRP to develop dedicated resources to support research data requests and analyses</p> <ul style="list-style-type: none"> • Includes provision of medical data for ISSMP Data Sharing Plans

WEBSITE ACCESS REMINDERS

Providing Data and Information to the Research and Operations Communities

NASA HOME PROJECTS MEDICAL OPERATIONS DATA REQUESTS JUST FOR FUN e-BOOKS

Life Sciences Data Repositories @ Johnson Space Center, Houston, Texas Search

NASA Human Research Program (HRP)

NASA's Human Research Program (HRP) conducts research and develops technologies that allow humans to travel safely and productively in space. The Program uses evidence from data collected on astronauts, as well as other supporting studies. These data are stored in the research data repository, Life Sciences Data Archive (LSDA).

More about HRP: [HRP Home](#) | [Human Research Roadmap](#) | [Evidence Book](#) | [Education & Outreach](#)

Research Data Repository: LSDA

NASA Space Medicine

Medical Data Repository: Lifetime Surveillance of Astronaut Health

Search Publicly Available Information and Data [RSS](#)

Data Request

Data can be requested from either or both repositories via a request form

Data Accessibility

HUMAN RESEARCH PROGRAM DATA ACCESSIBILITY

View this video presentation regarding the current status of Data Accessibility. In this presentation, Dr. Clarence Sams discusses the content of the Human Life Science Data, the data archive structure, the applicable legal documents and policies, and the methods for data access.

Missions in Progress

Expedition 26

Experiment **Mission** **Personnel** **Photo Gallery**

Biospecimens **Documents** **Hardware** **Dataset**

Life Sciences Data Archive URL: <http://lsda.jsc.nasa.gov>

Data Request Portal for Research and Clinical Data

The screenshot shows the NASA Life Sciences Data Repositories website. The navigation bar includes links for HOME, PROJECTS, MEDICAL OPERATIONS, DATA REQUESTS (highlighted with a red circle), JUST FOR FUN, and e-BOOKS. Below the navigation bar, the text reads "Life Sciences Data Repositories @ Johnson Space Center, Houston, Texas" and "Search". The main content area features a large image of an astronaut in space. To the right of the astronaut image, there is a "Data Request" button with a document icon and the text "Data can be requested from either or both repositories via a request form". A red line connects the "DATA REQUESTS" link in the navigation bar to a callout box on the right.

DATA REQUEST


User's Guide for Requesting NASA Data

Contents:

- Research Data Repository (LSDA)
- Medical Data Repository (LSAH)
- Data Categories
- Requesting Human Data
- Applicable Laws and Regulations
- Requesting Animal or Plant Tissues
- Request Form

The portal provides guidance to researchers on requesting data from the LSDA and LSAH repositories

Online Data Request Form



HOMERESEARCH PROJECTSMEDICAL OPERATIONS**DATA REQUESTS**JUST FOR FUNe-BOOKS

Life Sciences Data Archive @ Johnson Space Center, Houston, Texas

REQUEST DATA

Please use the form below to enter your data requests.
Please be as specific as possible and fill out the fields completely.
Acceptable alpha numeric character: a-z, A-Z, 0-9, @, \, dash, comma and dot.
Asterisks indicate required fields *.

Enter your Name: *

E-Mail: *

Phone:

Request Need Date:

 (MM/DD/YYYY)

Mission: (if applicable)

Data Type Requested: (if applicable) ☐ Tissue (LSDA) ☐ Research (LSDA) ☐ Medical (LSAH) ☐ I don't know

Grant or Contract Number: (if already in place)

*One request form for all
repositories
(LSDA, LSAH, and Animal
Biospecimens)

Annual Data Accessibility Survey

Help us improve our understanding of your needs

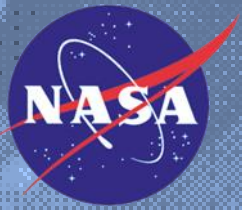
Complete the 2012 Data Accessibility Survey by Feb 22nd

Survey can be found at:

http://sisl.jsc.nasa.gov/Surveys/2012_Data_Accessibility/HTML/2012_HRP-Data-Access_revised.htm

Problems or questions with the survey?

Contact Dana.Bolles@nasa.gov



Backup

Clinical Data: Medical Tests Performed




Medical Operations


The Space Medicine Division mission is to optimize the health, fitness, and well being of flight crews.

Astronaut medical data are collected per requirements detailed in the [+ Medical Requirements Integration Documents \(MRID's\)](#). Data collected during these medical tests are generally housed in the Lifetime Surveillance of Astronaut Health (LSAH) repository. These test protocols are divided into areas as shown below. Each MRID will give an indication of the type of testing performed as well as the frequency of such tests.

Click on an category image for relevant MRID information:


 Behavioral Health and Performance

 Bone, Muscle, Exercise

 Cardiovascular

 Environmental Health

 Extravehicular Activity (EVA)


 Immunology

 Neurology

 Nutrition

 Radiation

 Therapeutics and Clinical Care

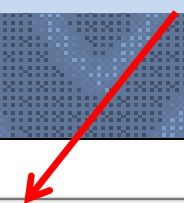
 View All Medical Requirements

Note: The Medical Requirements Integration Documents (MRIDs) reflect the Medical Requirements Requirements Document (AMERD), JSC 24834, the ISS Medical Operations Requirements Document (MORD) JSC 13956.

RELATED LINKS:

Data can be requested from this repository: [+ Request Data](#)
 More about [Space Medicine](#)
 Catalog of Medical Hardware used on the International Space Station: [Crew HealthCare System \(CHCS\)](#)

Annual medical exam & flight-related medical requirements




Therapeutics and Clinical Care

Discipline	MRID#	MEDB#	Medical Requirement Title
Therapeutics and Clinical Care	MR009L		+ Pre- and Postflight Physical Exam for Long Duration Crews
Therapeutics and Clinical Care	MR009S		+ Pre- and Postflight Physical Exam for Short Duration Crews
Therapeutics and Clinical Care	MR010L		+ Clinical Laboratory Assessment for Long Duration Flights
Therapeutics and Clinical Care	MR010S		+ Clinical Laboratory Assessment for Shuttle
Therapeutics and Clinical Care	MR011L	MEDB 1.6	+ Resting ECG
Therapeutics and Clinical Care	MR012L	MEDB 1.9	+ Dental Examination
Therapeutics and Clinical Care	MR013L		+ Audiometry for ISS
Therapeutics and Clinical Care	MR013S		+ Audiometry for Shuttle Crews
Therapeutics and Clinical Care	MR014L	MEDB 1.10	+ Ophthalmology Examination
Therapeutics and Clinical Care	MR014S		+ Pre- and Postflight Ophthalmology Examination for Short Duration Flights
Therapeutics and Clinical Care	MR015L	MEDB 1.12	+ Ultrasound Imaging (Sonography)

Other data from tests performed for clinical purposes may also be available

Online Information: Lifetime Surveillance of Astronaut Health



[HOME](#)

[PROJECTS](#)

[MEDICAL TESTS](#)

[DATA REQUESTS](#)

[JUST FOR FUN](#)

[e-BOOKS](#)

Lifetime Surveillance of Astronaut Health @ Johnson Space Center, Houston, Texas

Search

Current LSAH Design

The Lifetime Surveillance of Astronaut Health (LSAH) is a proactive occupational surveillance program for the astronaut corps to screen and monitor astronauts for occupational related injury or disease. The LSAH program examines the incidence of acute and chronic morbidity and mortality of astronauts, and defines health risks associated with the occupational exposures encountered by astronauts. From the evidence obtained through clinical testing, individually tailored follow-up medical examinations and surveillance for particular outcomes will be designed to track the astronaut population more rigorously and to capture sub-clinical medical events.

[+ Read More](#)

LSAH-Repository: Research Access to Medical Data

The LSAH Repository (LSAH-R) was established to implement a research component to enable access to astronaut medical data for approved research purposes. Informed consent for use of medical data for research purposes will be obtained from NASA astronauts. The LSAH-R will support research studies through epidemiologic analyses, data exploration and data visualization techniques.

Medical Tests Performed

The mission of the Space Medicine Division is to optimize the health, fitness, and well being of flight crews. As such, requirements exist to ensure accurate and consistent collection of astronaut medical data. Data collected during these medical tests are generally housed in the Lifetime Surveillance of Astronaut Health Repository (LSAH-R). Several types of medical data may be available through the LSAH-Repository.

[++--Read more](#)


Images Added to the Archive




Information regarding the LSAH history and current design, as well as how researchers can access this medical data, is online at http://lsda.jsc.nasa.gov/lisah_home1.cfm


Clinical Data: Access to LSAH Findings

- **Disseminate results of surveillance to participants, stakeholders, the research community, and the public**
 - The LSAH newsletter is published semi-annually as a communication vehicle for results gained through the surveillance process and changes to the program.
 - Surveillance results are also published in official NASA technical papers, books, and in peer-reviewed scientific journals
 - Other vehicles for communication of surveillance results are under development



National Aeronautics and Space Administration





THE LIFETIME SURVEILLANCE OF ASTRONAUT HEALTH

Newsletter

June 2010
Volume 17 • Issue 2

An Overview of the New Occupational Surveillance Program for the Astronaut Corps

BY: HEATHER J. HARTNETT, PhD

In 1992, the Longitudinal Study of Astronaut Health

This program is designed to fit the medical follow-up care to the individual, since everyone in this population has not been exposed equally to all hazardous

The Lifetime Surveillance of Astronaut Health (LSAH) is a proactive occupational surveillance program for the astronaut corps to screen and monitor astronauts for occupational related diseases. LSAH newsletters are published semiannually with the intent to keep participants informed and up to date on the program's findings. Click on the links below to view all LSAH newsletters published to date.

Year	Issue Date	Contents
2010	Vol 17 Issue 2 (Summer)	<ul style="list-style-type: none"> • An Overview of the New Occupational Surveillance Program for the Astronaut Corps • LSAH Repository Participation for Astronauts • Getting More Juice from the Lemon: The Lean Process • Health and Safety Tips for Travelers
	Vol 17 Issue 1 (Fall)	<ul style="list-style-type: none"> • Vitamin D Deficiency • The New Direction of Your Health Records • Pancreatic Cancer- A Silent Killer
2009	Vol 16 Issue 2 (Spring)	<ul style="list-style-type: none"> • Colorectal Cancer • Hospital Hygiene: Stopping the Spread of Nosocomial Infections • Trinitis: Will That Ringing Ever Stop?
	Vol 16 Issue 1 (Fall)	<ul style="list-style-type: none"> • Metabolic Syndrome: Fact or Fiction • Multiple Pair-Wise Comparisons • Chronic Diseases Surveillance
2008	Vol 15 Issue 1 (Spring)	<ul style="list-style-type: none"> • Don't Stop My Heart: Heart Disease Prevention • Hazardous Air Pollutants
	Vol 15 Issue 2 (Fall)	<ul style="list-style-type: none"> • A Brief Introduction to Bayesian Statistics • Ten Steps to Consider Before Taking Over-the-counter Medications

NASA/TP-2010-218124

**Atrial Arrhythmia Summit:
Summary Report**

Yael R. Buz, M.D., M.P.H.
Advanced Projects Physician
The University of Texas Medical Branch
NASA Johnson Space Center Bioregenerative Counter

June 2010



[illegible]

Online Searchable Catalog: Current Research Projects

Current Research Projects

Completed Research Projects

NASA Research Opportunities

Current Research Projects

- + Exercise Countermeasure Project (ECP)
- + Flight Analogs Project (FAP)
- + International Space Station (ISS)
- + Lifetime Surveillance of Astronaut Health (LSAH)
- + NASA Extreme Environment Mission Operations (NEEMO) Project
- + Non-exercise Physiological Countermeasure (NExPCM) Project
- + Shuttle Ongoing Research

Search Publicly Available Information and Data [RSS](#)

Experiment

Mission

Personnel

Photo Gallery

Biospecimens

Documents

Hardware

Dataset

INFORMATION ABOUT THIS DATA	
Data Set Name	Resting Gas Exchange in ISS Crewmembers
Data Set Description	<p>Pulmonary function tests were performed on eight crewmembers (7 male, 1 female) of the International Space Station who performed a total of 15 extravehicular activities (EVAs) and who followed denitrogenation procedures approved for EVA from the International Space Station. Of those EVAs, nine were performed using the Russian Orlan suits and six were performed using the US Extravehicular Mobility Unit (EMU).</p> <p>Source: Prisk GK, Fine JM, Cooper TK, and West JB. Pulmonary gas exchange is not impaired 24 h after extravehicular activity. <i>J Appl Physiol</i> 2005;99:2233-2238.</p>
Level of Processing	Analyzed - Microsoft Excel Spreadsheet
Data Files [Available online]	+ 96_E044_1950418134.xls File size : 35 kb Download
Measurements	<div>Alveolar dead space (VDAlv)</div> <div>Alveolar ventilation (VA)</div> <div>Average inspiratory flow rate (VT/TI)</div> <div>Breathing frequency (fB)</div> <div>Cabin pressure</div> <div>Carbon dioxide production (VCO2)</div>

Archived non-attributable data can be downloaded directly from the public website

Online Searchable Catalog: Research Projects


Current Research Projects

Completed Research Projects


NASA Research Opportunities

COMPLETED

RESEARCH



Historical Research Projects



+ Apollo Program

+ Apollo-Soyuz Test Project (ASTP)

+ Artificial Gravity (Fractional Gravity)

+ Bion Cosmos Flight Research

+ Biosatellite Program

+ Biospecimen Sharing Program (BSP)

+ Countermeasures Evaluation & Validation Project (CEVP)

+ Gemini Program

+ Lunar-Mars Life Support Test Project (LMLSTP)

+ NASA Ground-Based Investigations

+ NASA-Mir Program

+ Project Mercury

+ Shuttle Detailed Supplementary Objectives (DSO)

+ Shuttle Extended Duration Orbiter Medical Project (EDOMP)

+ Shuttle Life Sciences Research (Middeck)


+ Shuttle Life Sciences Research (Spacelab)

+ Shuttle Student Involvement Program (SSIP)

+ Skylab Program

HISTORICAL

RESEARCH



Shuttle Detailed Supplementary Objectives (DSO)

Conducted aboard the Space Shuttle, Detailed Supplementary Objectives (DSO) were medical investigations supplementary to the primary Shuttle payload performed voluntarily by the crewmembers. DSOs flown on Shuttle missions were designed to require minimal crew time, power and stowage. DSOs focused on studying adaptation to microgravity (specifically space motion sickness) as well as cardiovascular deconditioning, muscle loss, changes in coordination and balance strategies, radiation exposure, pharmacokinetics and changes in the body's biochemistry.

Related Experiments

+ Acceleration Detection Sensitivity (DSO 405)

+ Adaptation to Linear Acceleration After Space Flight (DSO 207)

+ Air Monitoring and Atmosphere Characterization (DSO 611)

+ Ambulatory Monitoring (DSO 416)

+ Anatomical Observation (DSO 422)

+ Animal Enclosure Module In-flight Test (DSO 421)

+ Assessment of Circadian Shifting in Astronauts by Bright Light (DSO 484)

+ Assessment of Human Factors (DSO 904)

Research Publications: Electronic Books

Links are provided to related websites

CURRENT NASA PROJECTS:



Human Research Program (HRP)

[Human Research Roadmap](#)
[Evidence Book](#)
[Science Progress Reports](#)
[SPACELINE Current Awareness List](#)
selected recent publications of interest

Lifetime Surveillance of Astronaut Health (LSAH)

The Lifetime Surveillance of Astronaut Health (LSAH) is an occupational surveillance program for and monitor astronauts for occupational health. The LSAH-R was established to implement a research component to enable analysis of astronaut medical data.
[View LSAH Newsletters](#)

Medical Operations

The [Medical Requirements Integration Document \(MRID Book\)](#) defines integration activities to support the medical requirements (MR) for both short-duration and long-duration human space flight for the Space Shuttle/International Space Station (ISS) programs. Or [View Individual Medical Requirements](#)
Recent publications: See ASTP and Skylab in Completed NASA Projects .

NIASA Technical Reports Server

Since it was first released in 1994, the [NTRS](#) serves as a valuable resource for students, educators, researchers, and the public for access to NASA's current and historical technical literature.

COMPLETED NASA PROJECTS:



Project Mercury

[Space Medicine in Project Mercury](#)

Gemini Program

[Gemini Mid-Program Conference](#)

Apollo Program

[Biomedical Results of Apollo](#)

Apollo-Soyuz Test Project

[Medical Report](#)

Skylab Program

[Biomedical Results of Skylab](#)
Recent publications: [The Skylab Medical Operations Project: Recommendations to Improve Crew Health and Performance for Future Exploration Missions](#)

Shuttle Program

[The Neurolab Spacelab Mission: Neuroscience Research in Space](#)
[Extended Duration Orbiter Medical Project - Final Report](#)

Lunar Mars Life Support Test Project (LMLSTP)

[Isolation: NASA Experiments in Closed-Environment Living](#)
[+ Whole book](#)
[+ Each chapter](#)

Fundamental Biology Animal and Plant Research

[Life Into Space, Volumes 1, 2 and 3 - Fundamental Biology](#)

Research program publications
can be read online or
downloaded

Animal Research Data: Biospecimen Sharing Program

- Animal biospecimens include organisms that have flown in space and subjects of related ground control studies
 - Available samples are surplus (unassigned) biospecimens
- Applicants may submit proposals specifically for analysis of materials obtained from this program or as a supplementary component of an experiment proposal in another research area

Search

Search within Results

Search: Using: All Words [+ GO](#) [+ Help](#)

Category
(Any Category)

Payload/Mission Participation
(Any payload/mission)

Species Studied
(Any species)

Session/Type
(Any)

[Reset](#) [+ GO](#)

The search term
“Muscular” returns the
following result:

Biospecimen Search Results

- You searched Category: Biospecimen Name= "Muscular"

Biospecimen Unassigned: Found 163 **Biospecimen Assigned: Found 890**

These tissues are available for research. [+ Tissue Requests](#)

Name	ID	Species	Collection Phase	Session Type
+ Adductor longus	4822	Rat	Postflight	Flight
+ Adductor longus	4823	Rat	Preflight	Basal
+ Adductor longus	4824	Rat	Postflight	Flight control
+ Adductor longus	4825	Rat	Postflight	Ground control